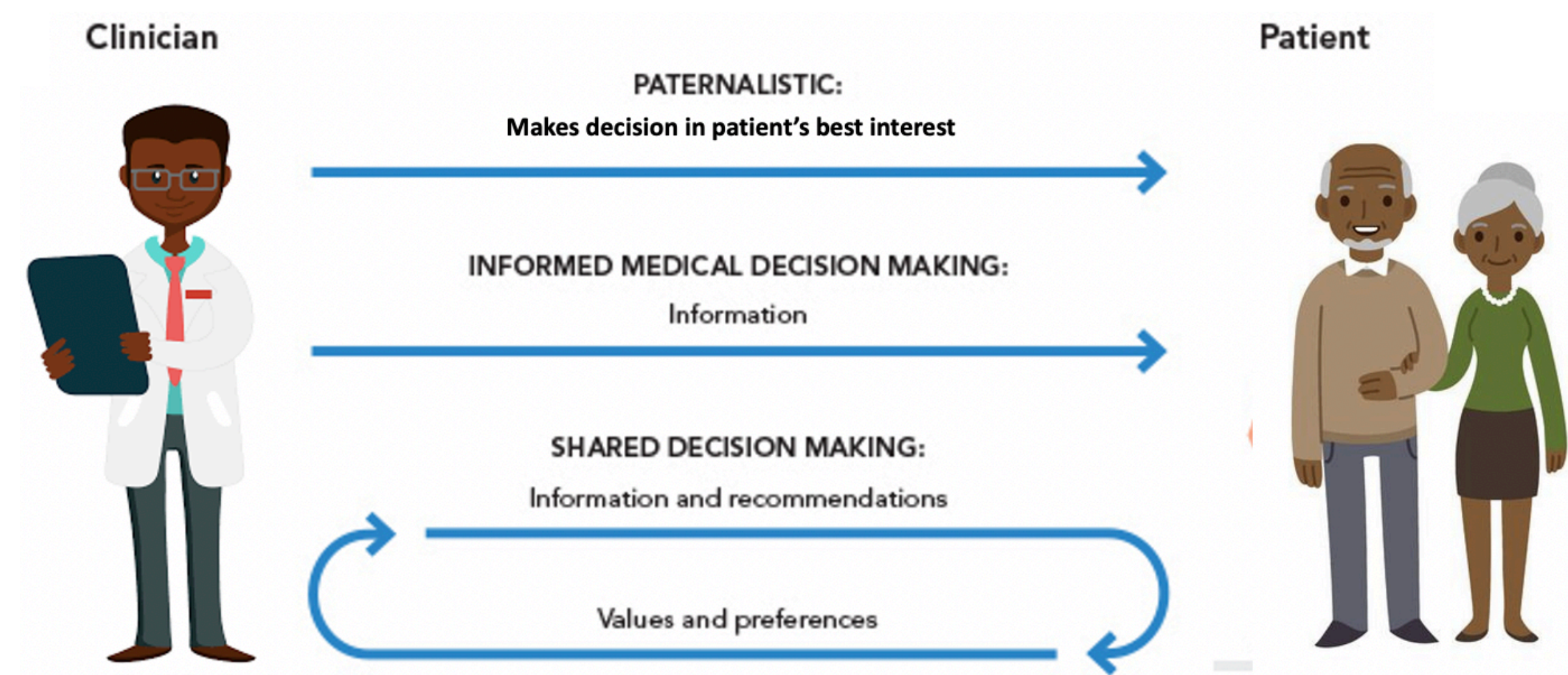


PURPOSE

- Decision-making about palliative chemotherapy for incurable cancer involves complex risk versus benefit assessments.
- The standard of shared decision-making (SDM) between doctor and patient is rooted in the Western principle of patient autonomy, and may not be readily transferable to diverse contexts, where different values may take precedence
- Ocean Road Cancer Institute (ORCI), the national cancer referral center in Dar es Salaam, Tanzania, provides free or subsidized care to approximately 5000 new patients per year
- We aimed to characterize the decision-making experiences and preferences of stakeholders at ORCI and to identify barriers and facilitators of SDM in order to develop strategies for improvement and to inform communication guidelines



METHODS

- Semi-structured interviews were conducted with a purposive sample of oncologists, nurses, and patients with advanced cancer at ORCI.
- Interviews were recorded, transcribed verbatim, translated into English, and coded using MAXQDA software, and thematic analysis was applied.

Providers (N=13)	N (%)	Patients (N=11)	N (%)
Female	8 (62%)	Female	8 (73%)
Position		Type of Cancer	
Physician	8 (62%)	Colorectal Cancer	3 (27%)
Nurse	5 (38%)	Kaposi Sarcoma	3 (27%)
Previous Communication Skills Training?		Esophageal	1 (9%)
Yes	7 (54%)	Cervix	1 (9%)
No	6 (46%)	Rhabdomyosarcoma	1 (9%)
		Prostate	1 (9%)
Mean interview : 43 min (35-60)		Mean interview : 31 min (18-50)	

RESULTS

Heterogeneity of Decision-Making Experiences

Paternalism:
“**Most often decisions are made by a doctor.** We assume our doctors are like directors; they know more than us, anything doctor suggest we see as the right way to go” – Patient 08

Informed Decision-Making:
“Before starting anything, we have a discussion or planning session. [That] means you have to **tell your client each and everything** [about treatment].” – Doctor 03

Shared Decision-Making:
“[I] usually talk to them about the disease itself, the treatment modalities, and any additional information, then I leave [it] to them to tell me their views. From there you can **elicit what are the things that are important to them.**” – Doctor 05

Community Misperceptions About Cancer Treatment

“When you’re home before arriving at the treatment facility you hear so much. People will tell you so many things – including that cancer treatment leads to death! **It was those stories which actually made us not to start treatment on time** as we were initially advised by he doctors.” – Patient 03

Treatment Adherence and Shared Decision-Making

“[Patients] like [when] we share information. You tell them these are the options that we have on the table and they really like it. **I think it’s easy to adhere to treatment when they understand.**” – Doctor 08

“If you [the doctor] don’t give the patients proper information, **it is more likely [they will] misunderstand** at some point and blame you, and the mistake will always be yours because you didn’t give them enough information.” – Patient 08

Change in Decision-Making Preferences Over Time

“**I think people are changing.** It is not like previously when they were not even asking questions. You could tell them: you have this and your treatment will be this. When you ask if they have any questions, they say no. Later you realize that they didn’t understand. Currently they ask questions and they try to understand what is going on.” – Doctor 04

“When I started **it used to be paternalistic.** I came to discover that there are a lot of patients [who] could not finish treatment and I decided to change. **Currently I consider their views on treatment and most of them are able to complete [it]** because we consider emotional and financial factors.” – Doctor 05

Facilitators of Shared Decision-Making		
Patient/Family Level	Provider Level	System Level
<ul style="list-style-type: none">Higher education and health literacy levelsPatient engagement(family/social network)	<ul style="list-style-type: none">Communication techniqueCollaboration among multi-disciplinary team, especially palliative care nurses	<ul style="list-style-type: none">Adequate time with patientPublic awareness and education about cancer

Barriers to Shared Decision-Making		
Patient/Family Level	Provider Level	System Level
<ul style="list-style-type: none">Limited knowledge or educationLack of sense of autonomy or empowermentLack of engagement	<ul style="list-style-type: none">Inadequate training in communication skills	<ul style="list-style-type: none">Community misperceptions and myths about cancer treatmentInadequate timeResource availability

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CONCLUSIONS

- There is **heterogeneity** across providers and patients regarding the type of decision-making model used, and the choice of approach **depends on situation-specific clinical and patient factors.**
- Paternalistic decision-making is more applicable in the context of curative treatment,** and when patients have lower health literacy and are less engaged.
- Providers generally agree **SDM is important in the context of palliative treatment decisions** and when **out-of-pocket costs are significant.**
- Patients generally placed greater importance on **providers’ communication style** and the **quality of clinical care** than SDM
- Participants believed that **SDM increases patient adherence** to treatment.
- Decision-making preferences have changed over time;** both providers and patients increasingly favor SDM over paternalism.
- One of the largest barriers to successful SDM is the **prevalence of misperceptions in the community regarding cancer treatment**
- Suggestions for improvement centered around **patient and public education about** cancer treatment to dispel common misperceptions, and implementing more provider **communication skills training.**